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ABSTRACT

Summarized is a discussion paper on existing elements of legal advocacy systems which could be considered as alternative models for adaptation by the respective states now seeking to plan and implement the advocacy mandate under Section 113 of Public Law 88-164 as amended in 1975 by Public Law 94-103, the Developmental Disabilities Act. Chapters cover the following topics: background on developmental disabilities legislation; existing advocacy mechanisms in Minnesota, Ohio, and New Jersey; policy considerations regarding such issues as requirements of independence, availability of legal resources, and authority to pursue remedies; and suggested criteria for advocacy systems. It is concluded that there are already a number of promising advocacy systems which now yield direct and tangible benefits to the developmentally disabled and their families. Appended is the table of contents of the full paper. (SBH)

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Advocacy

UNDER THE
DEVELOPMENTAL
DISABILITIES ACT

SUMMARY
OF A DISCUSSION PAPER
ON IMPLICATIONS
OF SECTION 113, PL 94-103

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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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I. PREFACE

This is a summary of a considerably longer discussion paper. The full paper, which will be made available at a later date, contains more extensive analysis, fuller descriptions, (especially of the multiple resources in the states of California, New York, and Massachusetts), extended documentation and a bibliography. The Table of Contents of the full paper is appended at the end of this summary.

The summary and the full paper are the products of a study conducted between February 1 and May 1, 1976, on a project grant from the Developmental Disabilities Office through its Region III Office to the Developmental Disabilities Center at Temple University. The Center is a University Affiliated Facility receiving on-going support under Part B of the Developmental Disabilities Services and Facilities Construction Act. The study is one of a number of advocacy-related studies and activities supported under various sections of the Developmental Disabilities Act.

The immediate purpose of this study was to identify existing elements of legal advocacy systems which could be considered as alternative models for adaptation by the respective states now seeking to plan and implement the advocacy mandate under Section 113 of P.L. 88-164 as amended in 1975 by P.L. 94-103.

During the study period, the author visited six states and conducted extended interviews with attorneys, citizens and professional providers of services involved in advocacy and service-related activities in those states. He also attended two national conferences on advocacy, which permitted him to talk with interested persons from many other parts of the country. He perused a variety of material, formal and informal, from as many sources as could be identified in the time available.

Of the six states studied by personal visit, three were found to have single preeminent models, each based on a different concept. In three states a multiplicity of entities, each performing some part of the task, were found. Because of the complexity of interaction among these agencies, the detailed description of them has been reserved for the full report. It should be noted that none of the models described in this summary

has stood the test of extended time and that, indeed, the new thrusts are in great measure a response to observed failures in pre-existing laws and systems which were originally addressed to many of the same ends. In presenting this material, the Developmental Disabilities Office hopes to give impetus to debate based on the sharing of current experience.

Although, as in similar studies, the project director has been encouraged to express his own considered views, which are not necessarily shared by the sponsoring government agency, the author and the Office concur that, while the principles underlying Section 113 are fairly clear, there will be, in a pluralistic federal-state system, a variety of equally valid modes of implementation. The ultimate purpose of the study, therefore, is to promote creative thought and indigenous decision-making at the state level, within the broad parameters established by the Congress.

Francis X. Lynch
Director
Developmental Disabilities Office

II. BACKGROUND

Advocacy for the developmentally disabled is an idea whose time has not simply come. It is long overdue. Without a system within which to vigorously assert their rights, disabled persons will remain second class citizens. A substantial consensus of opinion acknowledges that risk.

To multiply verbal guarantees of legal and human rights is not enough. Despite recent gains in recognizing the rights of the disabled, we have scarcely begun to heed the admonition, "Though shalt not ration justice." By creating effective advocacy centers, we hope to undo the impact of that rationing upon the lives of the developmentally disabled.

The aim of this paper is to raise some germane issues relative to implementing the requirements of P.L. 94-103. It points to various experiences that offer insight as to how these issues might be resolved. It will predicate no single, rigid model for slavish duplication. Its aims will be met if it provokes clarifying discussion, and if it brings useful information together in one place.

A central thrust of the new developmental disabilities legislation, Title II, is captioned "Establishment and Protection of the Rights of Persons with Developmental Disabilities." Within that title, Congress finds that persons with developmental disabilities have, among other rights, "a right to appropriate treatment, services, and habilitation for such disabilities." (Sec 111(1)). The core provision of Title II, entitled "Protection and Advocacy of Individual Rights," is Section 113. It reads:

> Sec. 113. (a) The Secretary shall require as a condition to a State receiving an allotment under part C for a fiscal year ending before October 1, 1977, that the State provide the Secretary satisfactory assurances that not later than such date (1) the State will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and (2) such system will (A) have the authority to pursue legal, administrative, and other appropriate remedies

to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the State, and (B) be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities. The Secretary may not make an allotment under part C to a State for a fiscal year beginning after September 30, 1977, unless the State has in effect a system described in the preceding sentence.

(b)(1) To assist States in meeting the requirements of subsection (a), the Secretary shall allot to the States the sums appropriated under paragraph (2). Such allotments shall be made in accordance with subsections (a)(1)(A) and (d) of section 132.

(2) For allotments under paragraph (1), there are authorized to be appropriated $3,000,000 for fiscal year 1976, $3,000,000 for fiscal year 1977, and $3,000,000 for fiscal year 1978.

Rights of the developmentally disabled are no more self-enforcing than rights of others. There is however, an obvious and special need for advocacy services for those so disabled in general, and the institutionalized in particular. Effective representation is currently provided to only a very small minority of developmentally disabled persons with socio-legal problems. The default of legal and human rights is occasioned in part by lawyers' lack of familiarity with mental retardation, autism and other disabilities which impair self-advocacy and the special problems arising from that condition or social status. And disabled people's use of the courts, lawyers and the law has tended to be episodic and unsystematic. No matter how aggrieved they feel nor how well intentioned their advocates, without access to sustained socio-legal backup assistance, violations of their legal and human rights may neither be identified nor corrected. In the majority of states just such a socio-legal backup center is conspicuously lacking.

The notion of advocacy abounds in conceptual and definitional confusions. We might well take heed of the National Baseline Study on Child Advocacy, which described the more amorphous usages as a "popular term some people apply to all the good things they want to

do for children."

Notions of advocacy under the new Developmental Disability Act are clearer and avoid just that problem. The Congressional provision on its own terms clearly limits and narrows the frame of reference of advocacy activities essential to satisfying the requirements of section 113. Protection and advocacy of individual rights are its focus, or what in Wolfensberger's schema would be primarily instrumental rather than expressive needs.

In reviewing the Act's history, it should be understood that the enactment of rights legislation for the developmentally disabled derived its impetus from the rediscovery by the courts, the media and the general public of the uncivil asylums in which the mentally retarded might be thrust. As Senator Javits expressed it for the Congressional Record:

> "The shocking conditions at Willowbrook in New York, and many other institutions for the mentally retarded throughout the Nation which inspired the bill of rights have not ended."
> (Cong. Rec. S. 9363, June 3, 1975)

The Conference Committee Report embodies agreement between the two Houses on the intent of the bill which was signed into law. In the words of House Report No. 94-473, Title II:

> "specifies rights of the developmentally disabled, requires programs assisted under the Act to have individual habilitation plans for the protection and advocacy of the rights of the developmentally disabled." (Page 41)

Lisa Walker is a Professional Staff Member to the Senate Subcommittee on the Handicapped and has had a long and continuous involvement with the Act. She described the intent of section 113 in part as follows:

> Given the nature of the client, the problems and complexity of the delivery system within States, it would be impossible to fulfill the intent of this provision without having a central point of access and coordination for this system...

> I do not think it is possible to develop a system within a State which would not have the ultimate ability to pursue a person's rights in Court. While the Committee was not thinking only of legal advocacy it would be impossible to comply with the provisions of the law (to pursue the legal, administrative remedies) without having legal counsel available to an individual through this system, nor could this system for advocacy protect the rights of developmentally disabled persons if it had to stop short of Court.*

The Congress attached special importance to the development of the advocacy system by making its existence by October 1, 1977 a condition for continued receipt of any State's funding under P.L. 94-103.

The system's primary mission is to uphold the individual rights of developmentally disabled persons. The system is to have distinct outreach capabilities. According to the Senate Report (94-160, page 38), it would serve as "a mechanism by which a developmentally disabled individual within the delivery system has the means to reach outside of the established delivery system for examination of situations in which his rights as an individual citizen may be violated."

While the intended system must have the authority and capability of seeking administrative remedies (administrative appeals, fair hearings, etc.), and other remedies (legislation, negotiation) legal services are clearly an indispensable element in seeking and securing certain technical remedies. Indeed, legal advocacy is no stranger to developmental disabilities law or programming. The Secretary, under the authority of section 145(a)(1), can make, and previously has made, project grants to "public or non-profit private entities for...legal advocacy." Similarly, under the authority of pre-existing statute"** services for persons with developmental disabilities" have been defined to include, inter

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* Interview of April 14, 1976.
** P.L. 88-164 as amended by P.L. 91-517, Section 401(m).

alia, "socio-legal services."

Throughout the legislative process, Congress was mindful, indeed, acutely sensitive to the need to assure the independence of advocates from providers of services and the avoidance of conflicts of interest. Hence, there is the strict condition that the system of rights advocacy be "independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities."

Lisa Walker amplifies:

> The intent here was to assure that the loyalties of this system be clear, that its role was only to protect and advocate the rights of the developmentally disabled. This extends not only to individual State agencies but also to grantees or other agencies or organizations which are receiving funding for social or habilitation services, or treatment from the State agency, and in that relationship become essentially an extension of the State's service delivery system.

In summary, although the language of the Act is broad, section 113 does impose conditions which provide some clear directions to the system and its designers. There can be latitude in meeting these Congressional directions without tipping over into formlessness or into the creation of a paper bureaucracy which fails to provide any direct assistance to developmentally disabled persons. While the system's components might be comprehensively stated, there is a real need to assure that any system include essential elements such as legal advocacy and a direct, coordinative relationship to consumers, to citizen and other independent advocates for developmentally disabled individuals, and to agencies with legal mandates to prevent abuse or assert rights.

III. EXISTING ADVOCACY MECHANISMS

This summary reports some current advocacy activities in three states exemplifying differing models each of which appears to meet the essential requirements of the Act. Many other states have elements which can be assimilated into an acceptable system.

Minnesota

Minnesota has some of the longest and most pertinent experiences in the design and operation of advocacy services.

Agency Mission and History

The Minnesota Developmentally Disabled Advocacy Project provides comprehensive legal services throughout the State of Minnesota to citizens with mental retardation, autism, epilepsy and cerebral palsy. Seventy percent of the Project's time is devoted to representation of clients in courts and administrative hearings. In addition to representation, the Project drafts legislation and regulations, engages in public education and training on the legal rights of the disabled, prepares training materials and advocacy manuals and handbooks for lay advocates, parents and consumer organizations, develops and evaluates systems of legal advocacy and operates as a backup center and clearinghouse on socio-legal matters affecting the developmentally disabled.

The Project has been in existence since 1973 and is funded by the Minnesota State Council on Developmental Disabilities. Some of the Project's activities include:

- ...Consultation and direct representation of more than 360 cases during its first 2 years of operation.
- ...Currently serves an open caseload of approximately 100 cases, representing about 160 persons. [As of December 30, 1975, it totaled 149 cases.]
- ...Approximately 230 people throughout the state have been trained to serve as lay advocates. These volunteers attempt to solve

problems at the local level and receive back-up support from the Legal Advocacy staff.

- ...Four major bills [drafted by Project staff] have been passed through the 1975 Minnesota Legislature, including: the Minnesota Mental Retardation Protection Act, probably the most progressive guardianship law in the United States, a zoning bill which lowers the barriers for developing future group homes for mentally retarded and physically handicapped persons: the legislation will help pave the way for community placement of at least 50% of the 3,700 state hospital residents.

- ...A wealth of training material has been developed and disseminated throughout Minnesota and to other states, including a 200 page Advocacy Manual soon to be published by the University of Minnesota Press.

The Developmentally Disabled Advocacy Project is operated by the Legal Aid Society of Minneapolis, a non-profit agency. The parent agency is a grantee of the National Legal Services Corporation, the Congressionally chartered public corporation. The Developmentally Disabled Advocacy Project has always received the full amount of funding it requested from the Minnesota Developmental Disabilities Council. It has recently been refunded for a fourth year, with a total budget of $110,000, comprising a developmental disabilities grant of $77,000 and a local match of $33,000. Previously, it had an annual budget of $46,000 in its first year, $77,000 in the second and $109,500 in the third. The Legal Advocacy Project has also received substantial private contributions.

With a staff composed of four attorneys and one paralegal advocate, the Project feels itself bound to a professional obligation of loyalty to its clients. The Code of Professional Responsibility, to which the attorney members are subject, unequivocally requires that professional judgment be exercised "solely for the benefit of the client and free of compromising influences and loyalties."* Furthermore, as a program within an agency funded by the Legal Services Corpora-

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* ABA, Code of Professional Responsibility, EC 5-1.

tion Act, its attorneys must be mindful of the Congressional findings that:

> attorneys providing legal assistance must have full freedom to protect the best interest of their clients in keeping with the Code of Professional Responsibility, the Canons of Ethics, and the high standards of the legal profession. [42 USC 2996(6), P.L. 93-355, Section 1001(6)]

Pursuit of Remedies

The Project has the authority and capacity to seek the full range of remedies specified in Section 113. It currently has an open caseload of about 149 files, some involving groups of clients, and has closed about 350 cases. In addition, it has offered assistance of an "advice only" nature to many other persons, and has engaged in a wide variety of public education, training, and material dissemination activities. The core of the Project's activity is directed to serving individual clients.

On matters of general direction and policy, the Project receives advice from a variety of sources and operates within a mesh of accountability checks. On matters of client representation, the project members are responsible to the client to use their professional judgment according to the dictates of the Code of Professional Responsibility.

In short, the Developmentally Disabled Advocacy Project aims at, and seems to be succeeding in training consumers and advocates to be sufficiently knowledgeable to protect and assert the legal rights of the developmentally disabled.

Ohio

An advocacy program may also be set up in a public agency. The Ohio Legal Rights Service, a statutorily created body, is one such fruitful initiative.

Agency Mission and History

On July 1, 1975, the Ohio Legal Rights Service (OLRS) was established to protect the rights of individuals in mental retardation institutions, those who had been in such institutions and those threatened with institutionalization. As part of the Bill of Rights

for Mentally Retared Individuals (Senate Bill 336, passed in mid-1974), ORLS was created by state statute to protect and advocate for the rights of this class of citizens.

The Service has three basic functions: "to receive and act upon complaints concerning institutional practices and conditions"..., to assure that all persons (within the Services ambit) ... are fully informed of their rights," and to assure that such persons are adequately represented by counsel in commitment proceedings and in any proceedings to secure the rights of such persons."

By statute, the Chief Justice of the Ohio Supreme Court appoints the Director of the Legal Rights Service for a term of five years. Douglas L. Rogers was so appointed in 1975, and proceeded to hire a staff which consisted of two other attorneys and one administrative assistant. The first year's appropriation for the fiscal year ending June 30, 1976 amounted to $83,000. The ORLS probably enjoys the distinction of being the state's smallest independent operating agency. Legislation is now pending before the Ohio legislature which would extend the Service's mandate and increase its staff. Bill No. 244 (which is supported by the Department of Mental Retardation among others, and has already passed one house) would amend Section 5123.94 to broaden the Service's statutory responsibilities in line with the population to be served by provisions of the Federal Developmentally Disabled Assistance and Bill of Rights Act, 197 .

By express statutory language, the Legal Rights Service is declared to be independent from other State agencies.

Pursuit of Remedies

The OLRS can employ a wide range of tactics in pursuing remedies for the people it represents. Under its regulations, the agency has powers to undertake activities on behalf of clients and non-clients. Activities for which the OLRS need not be representing an individual client include:

- "investigations or inquiries about institutional conditions or practices or conditions in the community". (II(B)(2))

- "general advocacy", which is not defined but would include policy statements or policy letters or testimony before a legislative committee. (II(B)(3))

- "giving advice". Its regulations state that as an information service, OLRS can give advice to private individuals and "other government officials over the phone or in person." There then follows a caveat of singular importance: "the advice should be given from the viewpoint of an attorney for a retarded individual, not a lawyer for that other government official. Finally, it should be made clear that any advice so given is merely an initial opinion, and will not bind OLRS action in the future. [II(B)(4))]

The major activity of the OLRS, however, is the representation of eligible individuals. Although OLRS takes a broad view of just who those persons are, it has, as a result of its scarce resources, adopted a policy of case selectivity to maximize its impact. By regulation, the OLRS had "discretion to determine through which cases it can most effectively use its limited resources to protect the rights of the classes of individuals" within its mandate. For example, the OLRS does not plan to represent clients in divorce, wills, or criminal defense cases. It usually will not represent individuals in damage actions against other individuals; nor will it generally represent individuals facing involuntary institutionalization proceedings. It will, however, attempt to insure that such individuals are represented by counsel through referral, court-appointment, or otherwise.

The OLRS strives to be client directed in its representational activities. Wherever possible, the client is in charge, and the attorney assumes the burden of advocating his rights, not reformulating his interests for him in the manner of traditional protective services.

The Ohio law expressly endows the Service with the power to sue in behalf of its clientele, and to sue a State agency. It does require the Service to pursue negotiations before filing actions.

The administrator may, when attempts at administrative resolution prove unsatisfactory, initiate actions in mandamus and

such other legal and equitable remedies as may be necessary to accomplish the purposes of this chapter. Relationships between personnel and the agents of the legal rights service and its clients shall be fiduciary relationships, and all communications shall be confidential, as if between attorney and client. [Section 5123.4(E)]

In the last analysis the Service is accountable to the legislature from which its mandate and its funding derive. As a creature of state statute, it owes its very existence to legislative authorization and its well-being to legislative appropriation. In theory, either could be terminated, and in fact the Service's appropriation is subject to annual review. Next year's budget will be approximately $115,000, which is seen as sufficient to support the activities of four attorneys, a social services worker, and an administrative assistant.

The Service maintains close collaborative ties with the Developmental Disability Law Reform Project of Ohio State University Law School. Funded by the Ohio Developmental Disability Planning and Advisory Council. the latter project is principally engaged in providing technical assistance and legislative drafting. It has drafted state legislation on a wide range of topics including rights to education, removing zoning barriers to group homes, prevention of patient abuse, and institutional reform. To avoid duplication of effort, the legal Rights Service has not been very active in legislative advocacy given the Law Reform Project's substantial contributions in that field. It also cooperates with a variety of other advocacy organizations.

New Jersey

With appropriate independence and authority, a public advocacy service may be established in the executive branch of state government. The New Jersey Department of the Public Advocate best exemplifies that approach.*

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* The Department is described in greated detail in a forthcoming Note in the Georgetown Law Review.

Agency Mission and History

The Department of the Public Advocate is a principal department, e.g., cabinet level department, within the government of the State of New Jersey. Chapter 27 of the Laws of 1974 establishes that Department as being comprised of five divisions: The Division of Public Interest Advocacy, the Division of Mental Health Advocacy, the Division of Citizens Complaints and Dispute Settlement, the Division of Rate Counsel, and the Division of Administration. The Office of the Public Defender is also an integral part of the Department, but remains technically separate for certain budgetary and other purposes. While Division duties are separately defined by the statute, the Department's general purpose is to undertake the representation of individual citizens and broad classes of citizens whose rights may be endangered. It is, in short, a public body for the advocacy and protection of citizens' rights against invasion from public or private action.

The Department was established in June, 1974 and can be said to represent a new concept and jurisdiction in State Government. Its objective is:

> to meet the new concept of highly visible and responsible State government, government under glass, by fulfilling the expectations of the citizens responsible action on the part of their government.
>
> Where an issue will be resolved by litigation, the Department must be able to provide adequate and expert representation on behalf of the public interest.
>
> Each Division of this Department has been established to contribute to the attainment of these goals.*

The first year appropriation for the new Department totaled $1.5 million. This year's budget request for "Protection of Citizens' Rights" totals $2,085,442, including elements for divisions of mental health advocacy ($918,827), public interest advocacy

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* Department of Public Advocate, Budget Request 1977, page 48.

($505,350), and citizens' complaints ($661,765).

The remainder of the Department's $15,457,728 total request largely supports activities of the Public Defender. All Divisions of the Public Advocate have served developmentally disabled citizens.

The Department is independent of any other State Department and by statute has the authority to take action against another department. Indeed, it is wholly independent of the Attorney General's Office.

Pursuit of Remedies

The jurisdiction of the Division of Public Interest Advocacy reveals the breadth of remedies that the Department is empowered to seek, i.e., the Division "may represent the public interest in such administrative and court proceedings .. as the Public Advocate deems shall best serve the public interest."

However, not all the remedies sought by the Department are of a legal nature. For example, the Division of Citizens Complaints and Dispute Settlement, is headed by a non-lawyer. That Division is established to perform both ombudsman and "hot line" type functions. The Office of Citizens Complaints is established to receive complaints from citizens relating to the administrative action or inaction of state government agencies and to forward these complaints to those agencies for resolution. Should a citizen find the response of a state agency unsatisfactory, the Division has the power to investigate and seek to have the respective state agency modify its action or request further action or different action. The Office is also empowered to recommend changes in state statutes or regulations, where, after investigation, the Office has determined that administrative action or inaction based on the particular statute or regulation is inappropriate. The Director has also described the operation of a toll-free, round-the-clock complaint by telephone service as "the most effective and most convenient means of contact between citizens and this office."

Through this hot line service, callers who just want help with local problems and do not know where to start may also be helped. Often they need a lawyer and the Division points them in the direction of a legal reference service.

The Division of Public Interest Advocacy, composed of attorneys and support staff, works closely with the Office of Citizens Complaints and serves, in the Department's words, "as a logical and necessary extension of the broad-based ombudsman concept of responsive State government." Thus, the State of New Jersey recognizes that while the Office of Citizens Complaints can resolve the majority of complaints received without resorting to formal action, "there is a clear need to provide legal representation and formal litigation for broad classes of New Jersey citizens in the public interest."

As an arm of State government, the Department of Public Advocacy is subject to a host of traditional checks and reviews. Its administrator, the Public Advocate, is appointed by the Governor, with the advice and consent of the Senate, to "serve at the pleasure of the Governor during the Governor's term of office and until the appointment and qualifications of the Public Advocate's successor." (Section 52.27E-3). The statute further stipulates that the Public Advocate shall be an attorney-at-law of the State and "a person qualified by training and experience to perform the duties of his office."

The Public Advocate has close working relationships with other state department heads and with the staff of the Developmental Disabilities Council. One of its divisions (Mental Health Advocacy) already cross-refers clients with the Citizens Advocacy program of NJARC, participating in workshops and conferences, and becoming involved in issues of lack of treatment or appropriate education for mentally retarded persons. According to its Division Director, there are already "good lines of communication" with the citizens advocacy coordinator, which offer the promise of providing help at a personal level for some Division clients.

On March 31, 1976, the Governor formally requested the assistance of the Developmental Disabilities Council in providing a "recommendation to him of a possible designation of an administering agency for purposes of the advocacy system in time to meet the planning guidelines."*

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* Memorandum from Lewis Kaden, Special Counsel to the Governor, to Catherine Rowan, Executive Director, Developmental Disabilities Council.

Other States

The other three states surveyed by a personal visit, Massachusetts, California, and New York, have such a wealth and diversity of advocacy resources as to preclude simple enumeration or the indepth discussion of any single agency. This is not to say that time-consuming and exhaustive compendiums of protective and advocacy resources and needs should be commissioned in those states. Such a literature is already quite extensive. New surveys might only paradoxically impede rather than facilitate the creation of the section 113 system. The full document, of which this is a summary, gives some indications of the many existing advocacy resources in search of a core center.

In addition to the states visited, material from other states such as Rhode Island, Washington, Pennsylvania, Florida, Michigan, Maryland, West Virginia, and the District of Columbia indicates a variety of resources now in place; while some do not of themselves constitute a system meeting all criteria, most could be effectively co-opted as components or in supporting roles.

IV. POLICY CONSIDERATIONS AND RECAPITULATION

This section summarizes some major conclusions to be drawn from legislative history (Section II, supra) and from information collected as to existing independent advocacy systems (Section III, supra). It highlights some basic issues which may arise in planning a section 113 system.

Requirements of Independence

The section 113 system must be "independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities." Scrupulous attention must be given to the avoidance of any conflicts of interest which could impair full and vigorous advocacy services. As expressed in one of the later draft introductions to the Act's regulations: "All possibility of conflict of interest must be avoided, and freedom of access to all appropriate remedies must be assured." (page 14). These two principles are absolutely central to the Congressionally mandated system.

It would, therefore, be wholly incompatible with legislative intent to designate as the implementing agency a habilitation and service providing agency operated, funded or otherwise administered by any State agency, which directly or indirectly provides or is administratively responsible for such habilitation and service, or represents the interest of the service providing agency. This view seems in accord with Assistant Secretary Stanley Thomas' letter of April 2nd to the Governors in which he wrote that in order for a state to qualify for continued DDO support, section 113 required that the system be placed in an "agency not already concerned with the delivery of services to the developmentally disabled." Equally, a State Attorney General's Office could not be so designated, since the charge of such an office is to represent other state agencies and to defend the validity and constitutionality of any challenged State law, rule, or regulation.

Requirement of Capacity to Seek Full Range of Remedies

The section 113 system must have the "authority to pursue legal, administrative an other appropriate

remedies to insure the protection of the rights" of the affected class of disabled persons. Those remedies minimally must include the authority and capacity to negotiate, inquire into, settle, appear in administrative and judicial proceedings, and initiate and defend suits on behalf of developmentally disabled clients, as well as to devise non-legal remedies.

Those charged with protecting the individual rights of such persons have a duty to employ the most efficacious means of ensuring them. One of the basic obligations to a client is to satisfy that client's claim in the most economical and expeditious way. This obligation will most often be realized by attempts at informal settlement or administrative rectification.

Other remedies which may be appropriate -- depending on the nature of the complaint -- include legislative advocacy, personal advocacy, public reporting and public recommenations. The states have discretion to supplement these remedies with others, consistent with the mandate of section 113, such as external ombudsmen and monitoring systems.

Rights to be Protected and Advocated

The system's object is "to protect and advocate the rights of persons with developmental disabilities ..." (Section 113) The rights to be encompassed include both the general rights enjoyed by virtue of United States and state citizenship, and the special rights that accrue by virtue of the disabling condition. Since there are no words of limitation nor definition of those "rights", rights must be construed in the widest way, to include any legal or other rights. Legislative history particularly stressed the constitutional and other legal rights of the developmentally disabled, giving express mention, for example, to efforts to secure rights under the Eighth, Thirteenth, and Fourteenth amendments of the United States Constitution.*

There are a number of restatements of the major rights of developmentally disabled persons. These rights include those contained in Title II of the Act,

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* Statements of Senator Taft, Senator Williams, Senator Javits, Congressional Record, June 3, 1975, S. 9362, S. 9367; See full report, Section II, supra.

those outlined in the President's Committee on Mental Retardation report, Century of Decision (pp. 58-64), and those established under the United Nations Declaration of the Rights of Mentally Retarded Persons (1971), and a more recent United Nations Resolution on Rehabilitation of Disabled Persons (1975). Disabled persons, of course, have the same rights, legal and constitutional, to which all citizens are entitled under the Constitution of the United States and their respective states, and under other laws, policies and practices of their respective governments. As the PCMR observed those same rights include the "rights of due process and equal protection of the law."*

Designation of Implementing Agency

In designating an implementing agency, States must first give heed to the dual requirements of independence and remedy-seeking authority. Beyond these, there are a number of other important considerations to be reviewed.

Existing or Newly Created Agency

If there is an already on-going mechanism for accomplishing section 113 purposes, an entirely new entity need not be created. Where an existing eligible agency is designated, there might be consideration of the need to strengthen or modify its role and capacities to discharge fully section 113 responsibilities.** Otherwise, an agency would need to be created or delegated to perform the requisite tasks in managing and implementing the system. These options are also reflected in Assistant Secretary Thomas' letter, which addresses itself to a state either designating an agency, for planning purposes, or using monies to implement "an existing plan."

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* Century of Decision at 58 (1976)

** See, for example, the April 9 letter of the New Jersey Public Advocate, Stanley C. VanNess, proposing an administrative restructuring of his agency to establish a "Bureau of Advocacy for the Developmentally Disabled."

Public, Quasi-Public or Private Nonprofit Agency

The agency with major responsibility for operating the section 113 system can be a public, quasi-public, or private nonprofit agency which can achieve the purposes and satisfy the dual requirements of the Act.

The strengths and weaknesses of those different options, in the abstract, are conjectural. Real agencies, of course, may be quite different from the generalizations about them. In the end, every system depends on the capabilities of the people it can attract and retain. No system, as the truism goes, is people-proof. In general, public agencies may have better access to information, while private agencies may have greater flexibility and freedom of action. Without commenting on their relative weight, I would note that interviewees offered some of the following pro and con arguments:

Public Agency

Strength:

1. Endowed with direct state authority
2. Access to state appropriations
3. Embodies public responsibility to the disabled
4. May have greater ease of access to officials and individual records

Weakness:

1. May be disbanded by the state
2. Subject to subtle and not so subtle influence through budgetary and other governmental processes
3. May have less flexibility to adapt to changing conditions given statutory, regulatory and other restraints
4. May become another self-protective bureaucracy

Quasi-Public Agency (Public Corporation and its Grantees)

Strength:

1. Combines best of public accountability and private initiative
2. Flexible vehicle for meeting specific needs which should be carried out at some distance from direct governmental control or regulation (e.g. Legal Services Corporation, Public Broadcasting Corporation)
3. Embodies public responsibility by its legislative charters, and its public funding, without making its employees government employees
4. Greater capacity to survive and perform its assigned mission

Weakness:

1. Funding source is still primarily public, so it is still in politics and may be affected by political interference.
2. Existing public corporations are sorely underfunded to meet public needs; new ones might not be exceptions

Nonprofit Private Agency

Strength:

1. Independence of government may strengthen its capacity and willingness to adopt active advocacy posture
2. If a tax exempt organization, may have greater chance of attracting private and charitable foundation donations
3. Greater freedom to innovate and to try out new methods and approaches
4. May encourage greater growth of consumer-oriented coalitions and their self-expression

Weakness:

1. Some have limited durability
2. May become overly dependent on grants

3. Unless strong client identification, may reflect own goals, not public goals
4. Public accountability may be blurred

Ultimately, of course, a sound framework for advocacy activities is essential, but the calibre and effectiveness of the advocates counts for more. One should look for the strongest and most vigorous advocates, not some doctrinaire choice of agency.

Legislative history and draft regulations make it clear that there must be a center and a point of coordination for advocacy activities. This must be a single agency. Indeed, Assistant Secretary Thomas' letter makes plain the intent to designate a sole agency to carry out operational responsibilities. While the Governor has wide discretion in the design phase, "only an agency which is not responsible for programs serving the developmentally disabled may have responsibility for the implementation and operation of the advocacy system." Even if this were not so clearly stated, considerations of efficiency, impact and limited funding would compel this strategic focus. This view is also in keeping with planning initiatives taken in New Jersey, Minnesota, and Ohio. While it should perform the most control functions, the core agency need not itself perform all advocacy functions.

Class of Persons to be Benefited

A broad consensus supports the view that the system should be statewide in scope, serve disabled persons who reside both in institutions and in the community, affect rural as well as urban areas, and be of value to all, and not just one or two types of developmental disability groups.

Maximizing Resources

One might well despair, and conclude that the task is impossible without substantially greater funding than that appropriated. Indeed, the goals will not be met, without a well-designed and well-focused advocacy approach. Notwithstanding the desire for comprehensiveness of scope and approach, it is imperative that priorities be chosen, and energies not be dissipated over too wide a range. Advisory councils to the system or other such bodies can be of help in the selection of those priorities.*

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* See Section III, supra, the Minnesota Experience.

A review of existing agencies described in part III, reveals certain strategies which have a multiplier effect whereby the vindication of one person's rights constitutes an equivalent gain for a far larger class of persons. For example, individual service cases done by lawyers of the Minnesota DD Advocacy Project have resulted in precedents benefiting many other disabled persons. Other examples of advocacy work with class-wide benefits include consent agreements; legislative advocacy or rule-making efforts to alter restrictive practices (zoning, education, etc.); negotiating to provide new forums or affirmative benefits; work with, and for organizations committed to strengthening the rights of the disabled; and representation of an individual in a way which draws attention to systematic denials of disabled persons' entitlements and proposes broad remedies. Examples of such statewide approaches now exist. In at least their initial stages, some have been funded for as little as $22,000 in Rhode Island, $50,000 in Washington State, and $46,000 in Minnesota.

Availability of Legal Resources

Several distinct types of legal resources might be fitted to assume major section 113 responsibilities. It should be noted that these potentially available resources already face many competing demands for their time. Further, they have different traditions, mandates and capacities. Moreover, even within a given law center category, diversity is great and generalizations misleading.

In the states cited directly above, those legal advocacy projects supported by DD Councils and state agencies were based in programs of the Legal Services Corporation. This brings to mind three considerations: (1) every state and territory has a legal services program, (2) like other on-going legal assistance projects, they can absorb a number of the startup and overhead costs of offering legal services on a limited budget. Given public funds outside the Legal Services Corporation, the programs need not impose any specific financial eligibility guidelines or cut-offs. Moreover, even using Corporation guidelines and funds, indigency is determined on the basis of the resources available to, and earned by the client, not by consideration of his relative means. The test of poverty for legal services purposes is whether the prospective client has insufficient personal assets at his disposal, and (3) without specially allotted

monies, for specially designated personnel, those offices may be unable to provide legal help to the developmentally disabled, or may be unlikely to provide more than occassional, and uncoordinated legal assistance to the disabled.*

With special grants from non-Legal Services Corporation sources, legal assistance programs need not be limited to serving the poor. In any event, many -- indeed far too many -- of the developmentally disabled would have little difficulty in being found indigent. In practice, legal services agencies like the Minnesota Project have not had income eligibility restrictions, nor difficulty in representing the developmentally disabled and their organizations.**

Public Defenders might also support, or at least coordinate their efforts with section 113 efforts. The same caveats as noted for civil legal aid would apply, except that the scope of some public defender responsibilities may be different than the civil programs (e.g., representation in juvenile court, criminal and some civil commitment proceedings).

In the District of Columbia, for example, the Public Defender Service has for many years supported a well-staffed advocacy unit within the public mental hospital. To date, that Service has not provided

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* John Donahue, Director of the Rhode Island Legal Services has cogently summed up the need for specially earmarked funds if isolated groups of clients are to be served among the welter of persons needing free legal services.

** Published draft regulations of the Legal Services Corporation tracking the language of the Act, state: 1610.3 Authorized Use of Other Funds A recipient may receive public or tribal funds and use them for any purpose for which they expressly were provided.

any analogous programs for the residents of the District's mental retardation facility. In contrast, the Public Defender's office of Los Angeles regularly represents the developmentally disabled and has recorded notable successes in protecting their due process rights.

Public interest law firms, with some notable exceptions, can only spend a limited fraction of their resources on issues affecting the disabled, if they are concerned with those issues at all. PILCOP, the National Center for law and the Handicapped and the Mental Health Law Project are quite distinctive among such firms in their devoted, inter-related and extended efforts for that clientele. In any event, public interest law firms tend to be in the largest metropolitan areas and are not found in all parts of the country.

Law schools are geographically widely distributed. While a few law schools have become affiliated with advocacy programs for the developmentally disabled, or have themselves provided some advocacy services, most have not. Since their basic mission is research and training, law schools may be reluctant, or be unsuitable to assume major responsibility for a program of on-going representation of the disabled, and their families and organizations. Some law schools do have clinical law programs, but these operate primarily to give students learning experience. The student's service work is necessarily limited by their other responsibilities, needs for substantial supervision, turnover and transiency.

In terms of the developmentally disabled, law school programs have also made contributions to research, curricular development, legislative drafting and advocacy; continuing legal education and sponsorship of conferences and training programs.

In many parts of the country, bar associations have formed committees to promote and advance the rights of the mentally disabled. That work has been spurred and tracked by the ABA's Commission on the Rights of the Mentally Disabled. The gamut of those activities is wide, and those committees may bring together practitioners who are knowledgeable and interested in this field.

Availability of Citizen Advocacy Resources

There are citizen advocacy programs in some 28 states. The nature and mission of those programs vary enormously, and some are discussed in publications by their promoters and organizers. Citizen advocacy for the mentally retarded, for example,* has been defined as "basically a one-to-one relationship between a capable volunteer (advocate) and a mentally retarded person (protege) in which the advocate defends the rights and interests of the protege and provides practical or emotional reinforcement (or a combination of both) for him." (NARC, Citizen Advocacy for Mentally Retarded Children, February, 1974).

Availability of Protective Services

Protective services are social or socio-legal services designed to prevent or remedy neglect, abuse or exploitation of children or of adults who are unable to protect their own interests. They may go beyond cooperating with the client to the point of acting on his behalf, and even without his consent, seeking legal authority to so act in general circumstances described by statute. Protective services for children have in the past frequently been directed against abuse of children by their parents. More recently, "third party" abuse has begun to receive more attention - as for example, abuse or neglect by institutional caretakers. Protective services for adults are more often addressed to risks run by persons whose ability for self-care and protection declines gradually with age, but who do not have relatives or close frineds to see that they are adequately fed, clothed, housed and cared for medically. Protective services for disabled adults other than the elderly have been relatively less well developed because of the previously widely held assumption that institutionalization offered the best protection.*

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* The Need for Protective Services for the Mentally Retarded and Others with Serious Long Term Disabilities, in UCPA, Conference Proceedings on Protective Supervision and Services for the Handicapped, pp. 181 (1968).

State welfare agencies have been the sponsors of most such services in the past. Such services, varying widely in scope and quality, exist in most states. However, since these services are located in a service delivering agency they do not in themselves meet the requirements of Section 113. Nevertheless, activities of protective service workers, like citizen advocates, can complement and enhance the effectiveness of the new advocacy agency. Given a proper identification and allocation of roles, the Section 113 agency's staff need not be called on to try to carry out social functions which others might better perform.

Interrelationship of Legal and Citizen Advocacy

There is an evident affinity and mutual interest between these various forms of client-directed advocacy. Legal, citizen and other forms of advocacy each strive to advance the rights and to express the interests of their disabled clients and proteges.

While they employ differing methods and scopes of attention, they are united by their involvement in representing that client's interests and viewpoints. As previously noted, these advocacy services can and do plan complementary roles. For example, in Minnesota, the Legal Advocacy Project provides lay and volunteer advocates with manuals, training materials, back up assistance, legal advice and the capability of pursuing remedies beyond the means of any volunteer. Furthermore, a number of existing legal advocacy programs including the Minnesota, New Jersey, Massachusetts SSI, Children's Defense Fund, PILCOP and half of all legal services programs already employ full-time persons who are not lawyers to perform paralegal and community outreach functions.*

Citizen advocates in turn can offer the clients of legal advocates an on-going, personal and less formal kind of assistance, as well as spotting violations of rights and referring clients to legal advocates where such assistance and support is appropriate. Without going into details, it is clear that a variety of formal relationships might be structured between legal and citizen advocates, of which New Jersey's preliminary planning and Minnesota's experiences are but examples.

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* National Paralegal Institute, The Significance of Paralegals in the Legal Services Program, 3 (1975).

Authority to Pursue Remedies

The statute requires the system to have "the authority to pursue administrative and other appropriate remedies" securing the rights of the disabled. The meaning of "authority" is not explained. Presumably, it may mean not only a capacity to pursue remedies, but an express delegation or mandate from the State facilitating the exercise of that remedy seeking capacity. For example, authority to do so might be conferred by contract from the State; Executive Order by its chief executive; or legislation or regulation by some duly empowered body. Such authority might be helpful in defining the system's mandate to defend the rights of developmentally disabled persons, and to insure access to facilities, to records (unless an individual client objects), and to part-time office space for the purpose of privately interviewing clients. Even if the agency designated to perform major responsibilities were a nonprofit corporation, there would be precedent for enfranchising it with a grant of authority. For example, some of the Societies for the Prevention of Cruelty to Children have had remedy-seeking powers allotted to them under state statute.

In a narrow sense, the authority of a nonprofit corporation as defined by its corporate purposes and by-laws might be sufficient, if it permits that body to seek the full-range of remedies to secure the developmentally disabled person's rights. Moreover, by designating an agency, the Governor will implicitly recognize its authority to seek those remedies.

Lisa Walker of the United States Senate Subcommittee staff described the term "authority" in this context as meaning "the legal capability of doing the functions described by the section."

She further explained:

> If they are going to use a state agency, they have to give it the authority to perform those functions, such as the authority of one state agency to sue another. For example, the New Jersey Office of the Public Advocate has that authority. If they are not going to use a state agency, it probably means the capability to carry out the functions

described in the law, including pursuing the full range of administrative, legal and other appropriate remedies. And it probably means that if the state makes a grant or signs a contract with a private organization it must spell out that the organization has authority, such as access to records, and to clients, etc., so that the agency can't turn around later and say - No, that wasn't part of your grant or contract.

Manner of Designation

Draft regulations state that:

> The Governor shall designate the agency responsible for administering the protection and advocacy system and shall approve the plan prior to approval of the Secretary. Such plans are to be submitted in accordance with these regulations and guidelines established by the Secretary. (Subpart C, S. 1386.80(b) (Sixth Draft)

Assistant Secretary Thomas' letter of April 2nd envisions a two-phase process of designation. In the first phase, the Governor is to designate an agency to receive funds for planning of the advocacy system. In the second, the Governor is to designate the independent agency to be given responsibility for the "Implementation and operation of the advocacy system." However, monies could be used in the first phase by a selected advocacy agency to continue or to start up activities described in Section 113.

In New Jersey and Minnesota, for example, the Governors have referred the matter to the State Developmental Disabilities Council for purposes of securing advice on those initial first phase functions. In New Jersey, the Governor formally requested the "assistance of the Developmental Disabilities Council to provide a recommendation to him on possible designation of an administering agency" to operate the system. Alternatively, the Governor could look to "a public or private nonprofit agency" to carry out the first phase functions or could even have them performed in his own Office. As California's position suggests, a state agency already acting as a service agency could and probably should defer to a non-provider agency in

designing the system. The grounds advanced by State Director of Health Lackner and his legal counsel are essentially that the advocacy system should be autonomous of the service agency and should be clearly perceived as such.

As Section III of this report makes plain, there are a number of plausible alternative designations including, but not limited to, the Chief Justice of the State Supreme Court or the statewide administrative body of the judiciary; a legal services corporation, public interest firm, or the State Public Defender; the State Planning Office; or some agency which is already implementing an existing plan for protection and advocacy of rights.

Where such a plan or program exists, States need not retrace the planning exercise, but may use these initial monies to strengthen that plan or program and provide immediate and direct advocacy services. Indeed, there is no reason why the designation process cannot be expeditiously handled so that advocacy offices may be established in many states on a pilot or other basis during the year prior to October, 1977, when the statewide system must be in place. Indeed, that very suggestion is contained in a letter from Health Commissioner Lackner to the Chairperson of the California Developmental Disabilities Council.

Personnel Requirements

Personnel needs follow the remedies to be sought and the rights to be effectuated. As mentioned previously, required staff will include lawyers, other professionals, and such paralegals, lay advocates, community outreach workers and citizen advocate coordinators as the particular state system design calls for. Some possible staffing patterns have already been described in the Section III descriptions of the Minnesota, New Jersey, and Ohio programs, and need not be reiterated here.

Interface with other Recent Legislation

Even without the section 113 requirement, the need for statewide advocacy centers would be apparent, particularly in view of the many pieces of recent legislation passed on both state and federal levels. Acts such as the Rehabilitation Act of 1973 and its amendments, the Education for All Handicapped Children

Act of 1975, and of course the Developmental Disabilities Act itself, bristle with new and unclarified rights. Similarly, recent state legislation such as the Massachusetts special education law require substantial efforts for implementation, monitoring and individual representation if those provisions are to be adequately understood and accomplished.

Furthermore, state law may establish new advocacy resources for the disabled which can be integrated into the advocacy system, such as New Jersey's Public Advocate, Rhode Island's Office of the Mental Health Advocate*, Maryland's Mental Health Information and Review Service** and the Massachusetts Mental Health Legal Advisors Committee. State law may also make some provision for meeting the needs for counsel in commitment and other court-based proceedings for this population. In other states, legislative proposals to create or extend advocacy services for the mentally disabled may have been made or may be contemplated. An advocacy center could begin to sort out these legislative strands and help avoid the creation of duplicative and ineffective parallel advocacy systems.***

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* Rhode Island Stat. S.40.1-5-22

** A.C.M. Art. 59 S.54.

*** The federal Education of the Handicapped Act, for example, requires, as part of its state plan, surrogates for children without familial support. In many, if not most states, that species of advocacy service has yet to be provided. Analogous examples could be drawn from vocational rehabilitation and other relevant fields.

Summary of Suggested Criteria

1. The advocacy system shall have a statewide impact, or potential for such impact.

2. The system's broad mission shall be to uphold and safeguard rights, particularly those rights intended to assure minimum levels of habilitation and to protect against abuse, neglect or exploitation.

3. The system's core agency shall be independent of public or private providers of services, and shall avoid any conflict of interest in representing its clients and performing its mission.

4. It shall have the capacity and willingness to pursue the full range of legal, administrative and other remedies. This shall include the authority and capacity to represent persons in judicial proceedings, administrative hearings and administrative appeals where those remedies are necessary.

5. The system shall be operational on a statewide basis by October, 1977.

6. If a state already is implementing an existing plan which meets the above requirements, it can use Developmental Disabilities office funds to carry out that plan to provide advocacy for the developmentally disabled before October, 1977.

7. Funds for the planning and operation of the advocacy system may be sought from other Federal, State and private sources, including other parts of the Act.

8. The primary allegiance and duty of the advocacy system staff shall be to represent disabled individuals or classes of individuals, and to promote their rights and interests.

9. The advocacy system shall take all necessary steps reasonably in furtherance of its mission, which may include:

   a. representing individuals or organizations without adequate representational resources on matters relevant to the protection of the

legal and human rights of developmentally disabled persons.

b. providing information on the rights of such persons to disabled persons themselves, their families, surrogates and lay advocates, their counsel and other representatives, professionals and public officials. Any advice should be given from the viewpoint of an advocate for the developmentally disabled.

c. engaging in legislative advocacy on behalf of the individual and class interest of developmentally disabled persons including testifying before relevant committees.

d. preparing manuals and conducting training sessions for lay citizens and other advocates on the rights of the disabled.

e. negotiating with the relevant agencies to secure the fullest application of the rights and benefits adhering to the developmentally disabled, and otherwise exhausting consultative and administrative remedies prior to seeking more formal remedies.

f. commenting upon, or otherwise participating in rulemaking processes or other formal administrative processes of substantial potential impact upon the rights of developmentally disabled persons.

g. appearing as amicus curiae or in other capacities in any forum in which rights of developmentally disabled persons may be determined.

h. preparing action-orientated reports on conditions which may adversely affect the rights and intrests of substantial proportions of developmentally disabled persons, and making appropriate recommendations.

i. receiving complaints as to violations, or non-compliance with the human and legal rights of developmentally disabled persons, and logging, referring, inquiring into and/or investigating those complaints.

j. referring developmentally disabled persons, where appropriate, to citizen advocates, lay advocates and other protective service agencies.

k. providing legal and other back-up resources to citizen and volunteer advocates on an as need basis.

l. coordinating and cooperating with other existing private and public agencies, including consumer groups, DD Councils and provider agencies as well as other advocacy and protective bodies concerned with the implementation, monitoring and enforcement of the rights of the disabled.

m. performing other activities and seeking other remedies reasonably related to the furtherance of the present and immediate rights of developmentally disabled persons.

10. The system may be operated in whole or in part by a public, quasi-public, or nonprofit private agency providing it meets the standards of independence stipulated in section 113(a)(2)(B) and these guidelines. Those who render assistance under this system must be free of any conflict of interest which would impair their capacity to meet their fiduciary obligations specified in guideline 8.

11. The personnel hired by the system may include advocates with legal, paralegal, paraprofessional and other professional training and qualifications. The advocacy system director must be a person qualified by training and experience to carry out the duties of that office. Each system must have an in-house legal rights component which should be directed by a person qualified to give legal opinions and to practice law in that jurisdiction.

The system should also have components capable of community outreach and information gathering activities such as citizen advocacy, lay advocacy, ombudsman or monitoring functions which are outside any service coordinating agency.

12. In those states in which the designated agency is non-public, it is recommended that the Governor designate a state official to serve as the liaison between the advocacy agency and service providing agencies and between the Governor's Office and the advocacy agency. This liaison official might be the executive director of the State DD Council, a member of the judiciary, some other official not otherwise involved in rendering services to DD persons. He or she should keep the Governor appraised of developments affecting the rights of DD persons. In no way, however, should the liaison official interfere with the advocacy staff in carrying out their professional responsibilities to clients.

13. In the design phase of a system, such a liaison official might be charged with collecting information or contracting for information or soliciting bids with respect to the design, establishment and implementation of the system contemplated by section 113.

14. While the Governor may solicit and obtain the views of a wide variety of sources including DD Councils, consumer groups, public officials and existing advocacy organizations, it is hoped that the designation of an agency to perform initial tasks would be made with a view toward maximizing the appearance (as well as the actuality) of fairness and the integrity of the intended system's independent advocacy functions.

V. CONCLUSION

Empirical studies of the American Bar Foundation show that 27% of all Americans have some legal problem in any given year. The developmentally disabled will, if anything, have more rather than less of these difficulties. Moreover, these problems will often affect their lives in the most basic of ways. It is not enough to say that the public must change its attitudes before unlawful discrimination can be ended. It is not enough to say that the branches of government are open to hear of their denied rights. Without advocates who will themselves seek remedies for wrongs, the courthouses, agencies, and legislatures are, for all practical purposes, closed to the developmentally disabled.

For most of our history, equal access to justice has meant no more than that the courts are not technically closed to any individual on the grounds of economic, political, or social status. We now know and recognize by law that open channels for complaint by and on behalf of the disabled are a necessary but insufficient step toward protection of their rights. Those rights must also be advocated vigorously in an array of administrative, legislative and community forums.

This report demonstrates that there are already a number of promising advocacy systems which <u>now</u> yield direct and tangible benefits to the developmentally disabled and to their families and friends. We really <u>do</u> know a great deal more than we think we do. Instead of re-inventing the wheel, let us realize that we have direct and forthright models of advocacy which already exist and which can be made to work for the developmentally disabled. Section 113 is an invitation to reinforce our alliances in common cause for the rights of the disabled. it would be shame ful indeed if that opportunity was obscured by narrow parochialism or lack of vision.

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